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Male Partners' Role in Latinas' Amniocentesis Decisions

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There has been relatively little research on men's experiences with fetal diagnosis or their role in their female partners' decisions about whether to be tested. This issue may be of particular salience in the delivery of genetic services to Latino groups, where it is often assumed that lower rates of genetic service utilization are linked to men's refusal to allow their wives to be tested. Here we present data from a multimethod study on the use of amniocentesis by Mexican-origin women in Southern California. We focus on the role male partners played in the women's amniocentesis decisions. Contrary to expectation, we found that women made the majority of the decisions about amniocentesis, although their partners' presence at the genetic consultation where the amniocentesis was offered proved an important predictive factor in amniocentesis uptake.

KEY WORDS: ethnicity; Latinas; AFP screening; amniocentesis decisions; male partners.

INTRODUCTION

Most research on decisions about the uptake of and experiences with fetal diagnosis has focused on women. To some extent, this is understandable. The tests are performed on women's bodies, women are typically the main focus of the counseling associated with its offer, and it is assumed that the work of raising a child with anomalies will fall largely on them (Kolker and Burke, 1994:59). Yet, in reality, few women decide entirely on their own about fetal diagnosis (Rapp, 1987; Rothman, 1986; Sandelowski, 1993). However, there has been little research on

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the role others play in women's decisions. Particularly surprising is the lack of data on how the offer of fetal diagnosis may affect male partners' experiences of their wives' pregnancies and the role they play in women's decisions about whether to be tested.

Instead, the limited research on male partners has been within the context of research on couples and genetic testing. For the most part, this work tends to assume consensus within a couple in attitudes, interests, and goals (see, for example, D'Amico *et al.*, 1992; Frets *et al.*, 1991; Hobus *et al.*, 1995; Schover *et al.*, 1998; Clark and DeVore, 1989). Nevertheless, there is ample evidence that couples often differ in their views on prenatal testing (Rapp, 1991), children with disabilities (Beeson and Golbus, 1985), and abortion for genetic reasons (Adler and Kushnick, 1982; Pauker and Pauker, 1987). But we know little about the full extent of these differences, how they are resolved (Lubs, 1979), or who has the final word when no consensus is attained.

Yet the few systematic studies on the subject find that differences within couples can be striking. For instance, Sorensen and Wertz administered questionnaires to 699 couples who sought prenatal genetic counseling. They found that a significant proportion disagreed on major issues: 55% identified different reasons for seeking genetic counseling, and 56% perceived different levels of risk for having an affected child. In addition, agreement on the seriousness of 11 potential problems associated with having an affected child ranged from only 55 to 67% (Sorenson and Wertz, 1986).

A similar pattern was seen in Kolker and Burke's much smaller sample, although women, not couples, were the source of their information. They report that only 16 of 22 married couples were equally favorable toward having amniocentesis, with the remainder equally split between the wife and the husband more strongly in favor (Kolker and Burke, 1994). Rothman's study of 60 primarily middle-class European-American women who accepted amniocentesis and 60 from the same background who declined provides fascinating insight into the dynamics of women's decision making. She found that women who themselves were inclined toward amniocentesis invariably discussed their decision with their husbands. However, about a fifth of those who declined never brought the matter up with their husbands, perhaps for fear of their partners' opposition (Rothman, 1986:53, 64; see also Scholz *et al.*, 1989).

For genetic counselors who work with Latino clients, men's views about prenatal diagnosis and their role in women's decisions may be of great interest. Evidence suggests that Latino men's wishes can be decisive in women's fertility behavior (Browner, 1979, 1986; Tucker, 1986). Moreover, many genetic counselors attribute Latinas' higher refusal rates to the view that men refuse to allow their wives to be tested (Garcia, 1995; Tatsugawa, 1995). Yet the frequency with which Latino men decide whether or not their female partners will undergo amniocentesis and their actual role in Latinas' decisions about fetal diagnosis remain unknown.

We set out to explore this issue with a group of women from Mexican backgrounds who were offered amniocentesis. We focused on the Mexican-origin population because it is large, young, and rapidly growing (California Department of Health Services—CDHS, 1995). Births to Mexican-Americans constitute 68% of the total among Latinos, with birthrates among recent Mexican immigrants the highest among the racial and ethnic groups for whom fertility patterns can be reliably computed (Ventura *et al.*, 1996:6, 40). Mexican-origin women and other Latinas are also at significantly higher risk than most other U.S. groups for some of the most common birth anomalies, including Down syndrome (Bishop *et al.*, 1997; Kuppermann, Gates, and Washington, 1996; Wilson, Chan, and Herbert, 1992) and neural tube defects (NTDs) (Stierman, 1995). For instance, neural tube defects occur twice as often in California-born Latino infants as in European-Americans, with the offspring of Mexican-born mothers at highest risk (Stierman, 1995:3). For all of these reasons, Latinos represent a population of growing importance for genetic counselors in the United States (Ota Wang, 1998).

We limited our sample to women offered amniocentesis because they had screened positive on the alpha-fetoprotein (AFP) blood test, which was developed to detect neural tube defects and can also help diagnose Down syndrome and other chromosomal anomalies. Beginning in the mid-1980s, the availability of this low-cost, noninvasive prenatal screening test vastly expanded the number, and changed the character, of the population of women offered fetal diagnosis. Until then, amniocentesis was the primary means for detecting birth anomalies. However, its high cost and chance of complications restricted its use to the relatively small number of pregnant women who were at high medical risk for bearing a child with an anomaly because of advanced maternal age or a reproductive or family history of birth anomalies. Within this population, the demand for prenatal genetic services tends to be strong and often client-initiated. Many such women are quite concerned about their ability to bear a healthy child and might not consider pregnancy were fetal diagnosis unavailable (Roghmann and Doherty, 1983; Hodgkinson *et al.*, 1990).

In contrast, women offered prenatal diagnosis because they screen AFP-positive are not particularly concerned about their ability to bear a healthy child prior to the positive screen (Green, 1990; Browner and Press, 1995; Press and Browner, 1997). Hence, their level of sophistication about and interest in genetic services is likely to be less strong. Few such women will themselves take the initiative in seeking out fetal testing; instead, the offer generally comes from clinicians. These factors may help account for the higher rates of refusing fetal diagnosis among recent Mexican immigrants (and women from other immigrant groups) in comparison with most native-born U.S. groups (Cunningham, 1998).

Given the above considerations, we began this study of the factors associated with Mexican-origin women's amniocentesis decisions with the following hypotheses: men made a significant proportion of the amniocentesis decisions

in our study population of women who were offered amniocentesis because they had screened AFP-positive; when there were differences within the couple as to whether the woman should be tested, the man's view would have prevailed.

THE CALIFORNIA AFP PROGRAM FOR PRENATAL SCREENING

This research was carried out within the context of California's state-administered program for prenatal diagnosis. Therefore, an overview of the program and the choices it offers pregnant women will help orient the reader to our findings. In 1986, the state of California mandated that all pregnant women who begin prenatal care prior to their 20th week of pregnancy be offered maternal serum alpha-fetoprotein screening for neural tube defects, Down syndrome, and other developmental anomalies (CDHS, n.d.). Between 7 and 13% of women screen positive low or positive high (Burton, Dillard, and Clark, 1985; Cunningham, 1998; Evans *et al.*, 1987; Greenberg, 1988), while the rest screen negative. A positive low screen indicates increased risk for Down syndrome and other chromosomal abnormalities; a positive high suggests the possibility of neural tube defects (anencephaly or spina bifida); intestinal, kidney, liver, or placental problems; or other poor birth outcomes, including fetal demise. In 1995, the state of California began adding unconjugated estriol and human chorionic gonadatropin to maternal serum alpha-fetoprotein to improve the accuracy of screening for Down syndrome and trisomy 18 and renamed its program Expanded AFP-Screening. From the 1995 initiation of the expanded program through the end of 1997, 825,804 women were screened, representing approximately 67% of women in the state in prenatal care by their 20th week of pregnancy (CDHS, 1998).

California's AFP-Screening Program is funded like an insurance pool, with a single fee ($115 as of 1995) covering the cost of the blood-screening test and genetic counseling, ultrasonography, and amniocentesis at a state-approved prenatal diagnosis center should a woman screen AFP-positive. Fees are paid for by most private insurers and by MediCal, California's Medicaid program.

Women who screen AFP-positive low or -positive high are advised to seek genetic counseling and further testing. At the conclusion of the genetic consultation, they typically are offered a high-resolution sonagram. In many cases, this sonagram reveals a benign explanation for the AFP-positive screen, most often a misdated pregnancy. Occasionally, the ultrasound reveals a structural anomaly such as anencephaly. If ultrasonography does not explain the reason for the AFP-positive screen, the woman is generally offered amniocentesis, which in California is performed through the 23rd week of gestation. Complications from amniocentesis are uncommon but include cramping, bleeding, infection, and, on occasion, fetal injury or miscarriage. The large majority of women who undergo amniocentesis receive normal results. Those who do not are informed as to what treatments

may be available for the type of anomaly found. They are also offered an abortion, which in California may be performed through the 24th week of pregnancy.

METHODS

Data for this investigation were drawn from three groups of Mexican-origin women who were offered amniocentesis because they had screened AFP-positive: patient charts, face-to-face interviews, and systematic observations. This multimethod approach enabled us to combine the strengths of quantitative and qualitative methodologies. The patient chart sample was larger and, because its data would be used anonymously, did not require informed consent. It therefore has less potential bias but is limited by the number and type of variables it contains. While fewer in number, the face-to-face interviews provided information on a wide range of issues associated with amniocentesis decisions which is not found in patient charts. Those data, however, were obtained from a self-selected group, which differed from the general population in ways that may introduce certain specific kinds of bias (see below for a discussion of this issue). In addition, the interview data depend on self-reports, which, for a variety of reasons, may be unreliable (Bernard, 1995). The observations provide data which do not depend on self-reports but may be similarly biased by factors related to self-selection.

Chart Sample

We reviewed the charts of all women who were patients at four Southern California genetics clinics between January 1 and December 31, 1996. We obtained the following sociodemographic and reproductive data for the 379 Spanish-surnamed women who screened AFP-positive: age, occupation, education, place of birth, religion, reproductive history (including any children born with a disability), previous experience with amniocentesis, AFP-screening-test results, amniocentesis decision for current pregnancy, whether any family member was born with a disability, and whether her male partner accompanied the woman to the genetic consultation. We developed our own codebook for coding the data and calculated descriptive statistics, including frequencies, proportions, means, chi-square tests, and tests of differences between two proportions using the Statistical Package for the Social Sciences (SPSS, 1998).

Interview Sample

We conducted semistructured face-to-face interviews lasting one to several hours with two waves of Mexican-origin women who were offered amniocentesis because they had screened AFP-positive and their male partners. For the pilot

phase, we recruited an opportunistic sample of 25 couples who fit the above criteria, and we spoke with them about the broad range of issues which oriented the research. Interviews were conducted by one of the two principal investigators (both professional medical anthropologists with extensive experience in the field of reproductive health, one of whom is also Latina) at a time and place of the respondents' choosing, most often their own home, and in their language of choice (either Spanish or English). For analysis, all interviews were tape-recorded and transcribed and retained in the language in which they were conducted. Questions used in the pilot study were analyzed for validity, reliability, comprehensibility, and content.

After analyzing the pilot data, we developed a semistructured interview guide which covered the following topics: background (including measures of social class, ethnicity, religious background and current practice, access to economic resources, gender-role attitudes, and division of domestic labor); reproductive history and experience with current pregnancy; factors considered in the amniocentesis decision; extent of the male partner's role in the woman's prenatal care in general and in particular in the decision about amniocentesis; access to social resources and the role others played in the decision about amniocentesis; perceived influence of medical personnel in the amniocentesis decision; knowledge and attitudes about disability, prenatal diagnosis, and induced abortion; and level of comfort and satisfaction with the amniocentesis decision and with the genetic consultation. Where necessary, standardized probes were developed in an effort to obtain the greatest validity and depth of response (e.g., "Have you attended church more often than usual to ask for help in making your decision about amniocentesis? If yes, how did you ask for help?"). Each respondent was asked each question from the interview guide in the same order, but to facilitate the flow of conversation and establish and maintain rapport, interviewers were trained to probe topics which were raised by respondents as they arose.

We next recruited a sample of Mexican-origin women who were offered amniocentesis because they had screened AFP-positive, and their male partners. Interviews were conducted by one of the two principal investigators or by one of four bilingual, bicultural fieldworkers trained by the principal investigators in the techniques of participant observation and in-depth interviewing (Patton, 1990; Taylor and Bodgan, 1984). Couples were recruited from three Southern California state-approved prenatal diagnosis centers. Of 991 potential participants, who were defined as women with Spanish surnames offered genetic counseling following AFP testing, 129 (13.0%) fit our criteria that at least one member of the couple be of Mexican origin and be willing to be interviewed. Of the remaining 862, 3% refused to participate, 32% were Latino but not of Mexican origin, 30% could not be reached by phone, 26% were not offered amniocentesis, and 9% were interested but unable to participate for various reasons, such as family illness or planning to move out of the area.

Interviews were conducted after women had decided whether or not to have amniocentesis, but some were still awaiting their results. All interviews were conducted in the participants' language of choice by one of the investigators or a trained bilingual interviewer (69% chose to be interviewed in Spanish, and 31% in English). Interviews were generally conducted in participants homes with additional data subsequently obtained by telephone.

The design was for women and men to have been interviewed separately so that each could tell her or his story in his or her own terms. However, 49% of the couples requested and were administered joint interviews. Because during the pilot phase of data collection we discovered that joint interviews provided rich insight into the dynamics of couples' interactions and their considerations associated with amniocentesis decision making, as well as interesting contrasts with the individual interviews, when it was requested we agreed to this variant in the design. However, we established a code which allowed us to analyze our data according to whether the interview was individual or joint.

All interviews were tape-recorded and transcribed by either the interviewer who conducted it or a bilingual secretary highly experienced in transcribing qualitative interviews. Quantitative and qualitative codebooks were developed in the two languages, and the data were coded in the original language of the interview (the translations that appear in this paper were done by the first author). Each question was coded either quantitatively or qualitatively or both by one member of the research team and was cross-checked by a second team member. SPSS was used to calculate descriptive statistics, including frequencies, proportions, means, chi-square tests, and tests of differences between two proportions. The qualitative analyses were conducted by assembling all data from all respondents on a single question or topic and reading through them to determine their content and patterns (Patton, 1990). Interview results reported here are based on combining the responses from the pilot and main samples, although data were not available on every variable from the pilot sample.

Observational Sample

We systematically observed the genetic consultations of 65 Mexican-origin women and their male partners who had been referred for genetic counseling between January 1996 and June 1998 because they had screened AFP-positive. We used a paper-and-pencil instrument of our own design to record data, including information conveyed, questions asked, and content and affect of interaction among participants (see Figure 1). Observational data were analyzed quantitatively and for content, with frequency counts made of the responses to the open-ended questions. The content analysis required that two members of the research team each read all of the data on a particular variable and independently score them.

Informant ID # _____ Date of Consultation: _____-_____-_____
Site: 0 1 2
3 4 5 other _____
Tick One: 1 woman 2 man 3 couple
A. Reproductive history
A.20 Experience with amnio
_____ 0 no
_____ 1 yes
A.21 Children born with defects?
_____ 0 no
_____ 1 yes; what?_____
A.22 Children died?
_____ 0 no
_____ 1 yes; of what? _____
A.23 Family with disabilities/defects?
_____ 0 no
_____ 1 yes: what?_____
W. Interaction with medical personnel
W.21 Verbal indications that the counselor is in favor of amnio
_____ 0 "it's logical"
_____ 1 "it reassures you"
_____ 2 "it's your decision . . . but"
_____ 3 other _____; _____
_____ 4 neutral
W.22 Physical indications that the counselor is in favor of amnio
_____ 0 smile
_____ 1 tone of voice: how?_____
_____ 2 other_____; _____
_____ 3 neutral
W.23 Verbal indications that the counselor is against amnio
_____ 0 _____
_____ 1 neutral
W.24 Physical indications that the counselor is against amnio
_____ 0 _____
_____ 1 neutral
W.25 Counselor allowed time for integration of information?
_____ 0 no
_____ 1 yes
X. Participation in the decision making
X.1 Woman asks the counselor questions
_____ 0 not at all
_____ 1 a little
_____ 2 somewhat
_____ 3 a lot
What questions?_____
X.2 Woman appears to be actively participating in the consultation
_____ 0 not at all
_____ 1 a little
_____ 2 somewhat
_____ 3 a lot
How?_____

Fig. 1. Quantitative Code Book III Observation of Genetic Counseling.
(Continued on next page.)

X.3 Man asks the counselor questions
_____ 0 not at all
_____ 1 a little
_____ 2 somewhat
_____ 3 a lot
What questions?_____
X.4 Man appears to be actively participating in the consultation
_____ 0 not at all
_____ 1 a little
_____ 2 somewhat
_____ 3 a lot
How?_____
X.5 Decision is made on the spot
_____ 0 no
_____ 1 yes
Notes:_____
X.6 Decision
_____ 0 refuse
_____ 1 accept
Y. Familiarity and knowledge about genetic counseling
Y.1 Do you know why you came?
_____ 0 no
_____ 1 yes
Words used by patient: _____
Words used by the counselor:_____
Z. Signs of interest in accepting amnio
Man:_____
Woman:_____
ZZ. Influence on each other's decision
ZZ.1 Man tries to influence woman
_____ 0 no
_____ 1 tried but did not convince her
_____ 2 succeeded in convincing her
ZZ.2 Woman tries to influence man
_____ 0 no
_____ 1 tried but did not convince him
_____ 2 succeeded in convincing him
NN. Recruitment
Accepts to participate: Name: _____
Telephone: _____
Best time to call: _____
Notes:

Fig. 1. *(Continued).*

RESULTS

Our results are organized into five sections: First, we present the sociodemographic and reproductive characteristics of the chart and interview samples and detail significant differences between the two groups. (Unfortunately, we were

unable to collect comparable data from the observational sample.) Second, we provide the results of our statistical analyses of factors associated with amniocentesis refusal and acceptance in the chart and interview samples. Next, data from the interview sample are offered to test our hypotheses. We then turn to two case summaries from among the 129 interviews, one from a couple who accepted amniocentesis, and the second from a woman who declined, in an effort to explain why. (Cases were selected for their representativeness.) Finally, we draw on our observational data to probe more deeply into how the presence of the male partner during the genetic consultation facilitated amniocentesis acceptance, while his absence had the opposite effect.

Comparison of Chart and Interview Samples

Tables I and II compare women in the chart and interview samples with reference to standard sociodemographic factors and reproductive characteristics. The two groups were similar on all dimensions except that women in the interview sample had more formal education and were more likely to have attended the genetic consultation accompanied by their male partners.

Factors Associated with Amniocentesis Decisions in the Chart and Interview Samples

In neither the chart nor the interview samples was a woman's amniocentesis decision associated with obvious background factors, including her age, level of

Table I. Sociodemographic Characteristics

Variable	Chart sample ($n = 377$)	Interview sample ($n = 129$)
% Over 34	34.0	25.8
% Born in Mexico	63.0	65.0
% Primary school or less[a]	47.4	26.1
% Catholic	82.2	83.4
% Family member with disability	18.7	16.1
% Previous amniocentesis	6.4	6.4
% Male partner present at genetic consultation[b]	43.9	56.1
% Accept amniocentesis	53.4	59.2

[a] $z = 4.23$; $p < .01$.
[b] $z = 2.39$; $p < .01$.

Table II. Reproductive Characteristics[a]

Variable	Chart sample ($n = 377$) Mean (*SD*)	Interview sample ($n = 129$) Mean (*SD*)
Previous pregnancies	3.17 (0.92)	2.88 (1.76)
Miscarriages	0.46 (0.73)	0.37 (0.71)
Induced abortions	—	0.21 (0.51)
Children born with anomalies	0.06 (0.24)	0.08 (0.29)

[a]No significant difference between groups.

education, religion and religious practice, and whether she lived with her male partner. (Information on civil status was not collected.) In both samples, the two groups of women had similar reproductive histories and personal histories of birth anomalies. Nor was an association found between amniocentesis decision and whether the woman screened AFP-positive high or -positive low (although only about a third of those interviewed could provide us with these data, and it also appeared inconsistently in the patient charts). Similarly, we were unable to collect data on gestational age to determine whether it was associated with amniocentesis decision because too few women were sufficiently aware of this information. (All data are available on request from the authors.)

We found few quantitative correlates of amniocentesis acceptance or refusal present in both the chart and the interview samples. In the chart sample, women who were Protestant and women who had no family history of birth anomalies were more likely to decline. In the interview sample, women born in Mexico were more likely to decline. The only variable which attained statistical significance in both samples was the link between amniocentesis acceptance and the male partner's presence at the genetic consultation (see Table III). The association was far stronger in the chart sample.

Our interviews show that men did not attend the genetic consultation for a variety of reasons, the most common being their difficulty getting or taking time off from work or their being out of town because of work obligations. In other cases, the men needed to watch their other children, could not find a place to park, were afraid to leave their car unattended for fear of theft, were uncomfortable or nervous in hospitals, or hadn't the patience to endure the long waits clinical consultations typically entail. In some instances, women actively discouraged their partners from attending because this gave the women more control, while in others, the situation was mixed: attending was problematic for the male partner, and the woman did not encourage him to make a special effort because she preferred to attend alone.

Table III. Differences between Women Who Accepted and Women Who Declined Amniocentesis

Variable	Chart sample ($n = 377$)[a]		Interview sample ($n = 129$)	
	Accept	Decline	Accept	Decline
Family member with anomaly				
No	99 (54.1%)	84 (45.9%)	—	—
Yes	32 (72.7%)	12 (27.2%)	—	—
Significance	$\chi^2 = 5.04$	$p = .025$	n.s.	
Male partner present				
No	41 (28.1%)	105 (71.9%)	23 (48.9%)	24 (51.1%)
Yes	105 (87.5%)	15 (12.5%)	54 (65.8%)	28 (34.1%)
Significance	$\chi^2 = 93.91$	$p = .000$	$\chi^2 = 3.67$	$p = .055$
Religion				
Catholic or none	131 (58.2%)	94 (41.8%)	—	—
Protestant	11 (28.9%)	27 (71.1%)	—	—
Significance	$\chi^2 = 11.22$	$p = .001$	n.s.	
Birth place				
Mexico	—	—	49 (53.8%)	42 (46.1%)
U.S.	—	—	28 (73.6%)	10 (26.3%)
Significance	n. s.		$\chi^2 = 4.38$	$p = .036$

[a]Numbers may not equal 377 because of missing data.

Test of Hypotheses with Interview Sample

We had hypothesized that in intact (though not necessarily coresident) Mexican-origin couples, women would cede the authority to make the amniocentesis decision to their male partners. We tested this hypothesis by analyzing the responses to the question "Whose opinion counted most in the decision whether or not to have amniocentesis?" Because we thought that it might be possible that couples in which the woman and the man were interviewed separately might respond differently from those interviewed together, we analyzed their responses both jointly and separately. These results are seen in Tables IV, V, and VI. As Table IV shows, contrary to expectation, more than half

Table IV. Whose Opinion Counted Most in the Amiocentesis Decision?[a]

	Women		Men	
Own	67	52.3%	17	14.3%
Spouse	17	13.3%	60	50.4%
Both	29	22.6%	29	24.4%
Other[b]	15	11.5%	13	10.9%
Total	128	100.0%	119	100.0%

[a]Numbers do not equal 129 because of missing data.

[b]Parents, in-laws, siblings, friends, clinicians.

Table V. Whose Opinion Counted Most in the Amniocentesis Decision? Women Interviewed Separately and Jointly with Partner

	Separately		Jointly	
Own	36	55.4%	30	48.4%
Spouse	10	15.4%	7	11.3%
Both	9	13.8%	20	32.3%
Other[a]	10	15.4%	5	8.1%
Total	65	100.0%	62	100.0%

[a]Parents, in-laws, siblings, friends, clinicians.

the women said their own opinion counted most in the amniocentesis decision, while an additional 23% described the decision as a joint one. Less than 12% said their partner's opinion had more weight than their own. For the most part, the women's partners agreed with the women's assessments, although the men were slightly more likely to give their own opinion more weight than the women did in the amniocentesis decision (differences between genders not statistically significant).

In separately analyzing the responses of women and men interviewed jointly and separately, an interesting pattern emerged. Although the difference between groups did not attain statistical significance, women interviewed alone were slightly more likely than women interviewed jointly to say their own opinion held the most weight, but they were also slightly more likely to say that it was their partner's. In contrast, they were far less likely to indicate that it had been a joint decision. Similarly, men were far more likely to take independent credit for the decision when interviewed separately and less likely to say the decision was joint, although again, the difference did not reach statistical significance. It is impossible to determine from these data whether couples who asked to be interviewed jointly were more likely to make joint decisions, or whether the other partner's presence contributed to the response they gave.

Table VI. Whose Opinion Counted Most in the Amniocentesis Decision? Men Interviewed Separately and Jointly with Partner

	Separately		Jointly	
Own	12	20.0%	5	8.8%
Spouse	31	51.7%	28	49.1%
Both	11	18.3%	18	31.6%
Other[a]	6	10.0%	6	10.5%
Total	60	100.0%	57	100.0%

[a]Parents, in-laws, siblings, friends, clinicians.

Nevertheless, what is consistent in all of the above data is that the role of the male partner in these Latinas' amniocentesis decisions was complex. For if, in fact, it was mostly women who decided, what would be the significance of the very strong statistical association between male partners' presence at the genetic consultation and amniocentesis uptake, particularly in the chart sample? We might hypothesize that women who attended the genetic consultation accompanied by their male partners had already decided to have the procedure and had asked their partners to accompany them to offer moral or material support. In contrast, unaccompanied women may have already decided against the procedure and therefore may have had no motivation for their partners to attend. Yet we find no evidence for this scenario. Only 14% of those interviewed said they had made their decision prior to the genetic consultation; the rest had decided at the hospital following the genetic consultation or subsequently.

We therefore now turn to two case studies, one of a woman accompanied by her male partner who accepted amniocentesis, and one of an unaccompanied woman who declined. We show that neither woman had made her decision prior to the genetic consultation. Yet in the first case, the husband's presence reinforced the woman's apparent prior inclination to be tested, while in the second case, the man's absence in and of itself appears to have contributed importantly to the fact that the woman ultimately turned down the procedure. In both cases, women viewed their partners as providing support (*apoyar*) for whichever decision the women made, rather than dictating a course of action. Background data provide a context for the considerations these individuals took into account when arriving at the course each one chose.

Case Summaries

Couple Who Accepted

Susana and Adrian grew up in working-class families in Jalisco, Mexico. She was 27 and had been in the United States since 1988; he was 25 and had been here since 1994. Both had completed the entire six years of primary-school education in Mexico. She was a homemaker, and he worked as a parking-lot attendant. This was her second pregnancy; they had a three-year-old son. There was no history of birth anomalies in either family. The couple requested a joint interview.

Susana told us during the interview that she was distraught when she received the AFP result. She said she cried and cried, fearing the baby would be born with Down syndrome. Adrian was also worried when Susana gave him the news, worried—and confused. He explained, "When Susana told me about the test result, I began to think, how could this be? I don't take drugs, I don't beat my wife. I was really frightened."

Susana asked her husband to take time off from work so they could go together to the genetics consultation. She said she wanted him with her because "the husband

should also know the risks." Adrian was happy to comply: "I went to give her support; it's better for us to be together to decide." Susana had already read about amniocentesis, but for Adrian it was "something new." They found the counseling complete and comprehensible and felt all their questions had been answered. The high-resolution ultrasound revealed no obvious problems.

They accepted the amniocentesis virtually on the spot, taking only "five minutes" to decide. Adrian explained, "We accepted to get rid of the doubt" (*para sacarse la espina*). Susana concurred and continued, "And also to take advantage of being there and not having to return another time." When asked what they had talked about while making their decision, Susana spoke first. "I told [Adrian], I'm afraid. . . ." He continued, "I said to her that in any event we have to do this, as long as we're here." She added, "I told him that for my baby I'd do whatever was needed. I didn't think I was going to have a miscarriage." He agreed. "The risk of miscarriage was low," he said. "There wasn't a danger."

Neither saw the necessity for involving anyone else in their decision. They said their faith in God gave them the strength they needed to decide. Abortion was not an option for either of them should the amniocentesis have proven positive. "We'll accept it however it comes," said Susana. "If my child is going to be like that, God knows why He sent me it, and that's the way I'll receive it."

In closing the interview, we again asked, why they had accepted amniocentesis. Adrian spoke first: "They told me they had to investigate why it came out positive low. They said they had to get to the bottom of it. It had to be done . . . for the good of the baby." Susana agreed. "[I wanted] to find about my baby's health [and about] what I should expect. And to be calm. I also feel doubts and . . . what affects me is going to affect the baby. I had to resolve my doubts."

Woman Who Declined

Silvia, age 29, had been in the United States for 10 years. She had grown up in a village outside Guadalajara, Mexico. Her father was a day laborer, her mother an itinerant clothing peddler. She had four years of formal education in Mexico. Her husband's background was similar, although he had completed six years of primary schooling. He worked in construction; she was a homemaker. Although Silvia and her husband already had three daughters, they desperately wanted a son. There was no history of birth anomalies in either family.

During the interview, Silvia explained that she casually accepted the AFP test, not really understanding what it was for. And she initially attributed little significance to the AFP-positive result: "They said . . . that I had low blood. . . . At the time, I didn't know [what it meant]. . . . I have three girls and everything [was] always fine. . . . Then, when they told me my blood was low . . . I thought that because I was eating little, because I was vomiting, that's why the protein was low. . . ."

Silvia went alone to the genetics consultation because her husband was working out of town at the time. Ordinarily, he drove her to her prenatal appointments

and watched their daughters while she saw the doctor. She found the consultation unsettling. "That's when I began to worry," she said. "Up until then I had been calm.... But in the hospital, they explained things that I didn't want to hear [things that could be wrong with the baby]." She continued, "I felt I was in a fog. They're saying so many things and how are you going to know if you are understanding or not?"

The high-resolution ultrasound revealed no apparent problems, which Silvia found reassuring: "They told me that the ultrasound result [showed] that everything was fine. It was in agreement with the dates of my menstruation. So I said to myself, 'Why if everything is fine do they want to continue digging (*escarbando*)?'"

When she was offered amniocentesis after the ultrasound proved normal, Silvia told the counselor that she needed time to decide. Later that same day, however, something unexpected occurred. "They say God advises us in the most curious ways," Silvia explained. "The day I came back from the clinic, my sister-in-law was there with my kids. She had picked them up for me at school because I had gone to the doctor. And we were chatting, not about anything in particular because she didn't know why I had gone. And she said, 'Know what? Albert's teacher [Albert is the sister-in-law's son, Silvia's nephew] just lost her baby after a test they did.' I said, 'It can't be.' It gave me a blow... I was speechless.... [I took] it as a sign... because in the clinic they had explained to me that statistically there was very little risk of miscarriage. But look. There and then I realized what could happen."

Silvia then talked with her husband but was afraid to tell him too much about her situation for fear he would urge her to be tested. She was even more fearful he would want an abortion if the diagnosis proved to be positive. Instead she emphasized what she had heard had happened to Albert's teacher. He replied, "Know what? We haven't had luck until now [referring to the fact that all their children had been girls], and this one could be a boy, and if they stick you and something happens, it will be our fault." In the end, she said, he gave her all the support she needed and was in complete agreement with her decision to decline amniocentesis.

Observational Sample

Our systematic observations of 65 genetic consultations with Mexican-origin women who were offered amniocentesis reveal that the dynamics in these two cases were not unique. Instead, they were consistent with the view that the appropriate male role is "to support" (*apoyar*) the woman in whichever decision she chooses. Evidence for this view was seen in differences in the meaning women and men attributed to having screened AFP-positive and differences in the ways they interacted with their genetic counselor.

Men and women appeared to approach the genetic consultation quite differently. We found that while in general there was not a high level of interaction

between counselors and patients, when clients did initiate interaction the men were less openly fearful than the women and appeared much more comfortable in the situation. Many women sat through the genetics consultation with tears in their eyes. Others stared fixedly at the counselor. Still others sat stiffly on the edge of their seats, some with their eyes averted, others incessantly worrying any object they could find: a balled-up tissue or handkerchief, a wallet, or a set of keys. The men, on the other hand, acted relaxed, more confident, and in charge. They sat back comfortably in their seats and spoke directly to the counselor. Some came with a written set of questions, others took notes throughout the session, behaviors never seen in the women. Some would gently touch their wives on the shoulder from time to time or squeeze her hand.

Men and women also sought answers to different types of questions. Women were more likely to express "corporeal" concerns (e.g., how painful amniocentesis is, how likely a hemorrhage is, whether there is a danger of provoking uterine contractions, whether the fetus could be injured during the procedure). In contrast, the men's concerns were more "informational" (e.g., how chromosomes are counted or their condition assessed, how reliable amniocentesis results are what the statistical risk of miscarriage is, how competent the doctors are who administer the procedure) or even peripheral (e.g., how new the computers are, what kind of training is needed to run them).

Observing the men, we also found that many tended to act as spokesman or an interpreter of biomedicine. Some repeated what the counselor said to their wives, in an apparent effort to allay the women's fears. For instance, Juan explained to his wife, Lisa, "Now, you see! [The counselor] says [the amnio] is less painful than a dental extraction." Other men took it upon themselves to articulate what they believed were their partners' concerns. Rogelio, for example, sought to take the counselor into his confidence when he said, "I know she wants to do it [the amnio], but she's afraid." And many women, like Marisa, reported that their husbands' presence was a genuine source of assistance. "I was dizzy. I couldn't even hear what they were saying." she explained. "But when he saw that the risk of miscarriage was very, very rare, I told them yes." (Note the construction: *He* saw the risk of miscarriage was rare, and *I* told them yes.)

The men present at the genetic consultation, then, seemed to serve as a bridge between the world of medicine and their wives, helping to control and to "contain" the women's fears (cf. Feohrenbach and Lane, 1990). As Roberto explained, "I went to the genetics consultation to help her. And to know. Because he who does not know is like he who does not see." We asked whether helping his wife "see" could have influenced her decision. He replied, "Of course. I told her that she couldn't be swayed by what she hears on the streets, that she had to see the truth of science."

The experience of unaccompanied women was quite distinct. The above case of Silvia, who attended the genetic consultation by herself and ultimately declined amniocentesis, makes this clear. Although she initially attributed little significance

to the positive AFP test, she became very upset at the genetics clinic; she said she was "in a fog" throughout the consultation. "They're saying so many things and how are you going to know if you are understanding or not?" she explained. In contrast, accompanied women had help putting what the counselor was saying into perspective.

Although unaccompanied women generally declined amniocentesis, few did so on the spot. Most indicated that they wanted time to think over their decision. Taking time "to think it over," however, was predictably linked with amniocentesis refusal. For once in their home environments, women were generally counseled by relatives, friends, and even strangers, who provided a variety of reasons for refusing the test. The example of Silvia, who after leaving the consult learned from her sister-in-law about a miscarriage attributed to amniocentesis, illustrates this well. In these situations, a husband is dependent on his wife's report of the genetic consultation, so he cannot serve to counterbalance the woman's fears, even if he were so inclined. But since a man's role in this arena is construed as supportive, not determinative, it is unlikely most would even have tried to convince their wives to consent to something the women were uncertain about.

DISCUSSION

Potential Sources of Bias

Methodological

Although we made every effort to strive for consistency in the data collection processes, potential bias may have been introduced because of the interviewers' inability to understand the meaning of certain questions or because of inconsistency between or within interviewers in the administration of the interview guide or inaccurate or inconsistent translation or transcription. We sought to minimize these potential sources of bias through the use of standardized interview guides, by carefully training our interviewers during the pilot phase of the research, and by frequently checking the work of the transcriber against the tape. Another potential source of bias is that individuals may have failed to accurately respond to the questions we asked, given that many of the topics were of a personal or otherwise sensitive nature. We sought to minimize this source of bias by beginning the rapport-building process during the period of recruitment and continuing it at the start of the interview, and by recruiting a research team made up of individuals either from the same cultural background as the study participants or with decades of experience working with similar populations.

Sampling

The fact that the research design required both members of the couple to agree to a lengthy interview may have biased the sample toward couples in which the men were more involved with their families and their wives reproductive health care. These effects are seen in comparing the proportion of male partners who attended the genetic consultation in the chart and interview samples (see Table I). Nevertheless, the fact that the chart and interview samples were quite similar on the vast majority of sociodemographic and reproductive characteristics and had similar rates of amniocentesis acceptance leads us to conclude that the two groups were in other ways quite similar.

Our review of the chart and interview samples yielded few noteworthy findings. Just over half of both samples accepted amniocentesis following a positive AFP screen. These figures are somewhat lower than statistics compiled by the state of California for Latinas in similar situations and significantly lower than acceptance rates by European-American, Asian-American, and African-American women (Cunningham, 1998). Few sociodemographic characteristics were significantly associated with amniocentesis acceptance or refusal, and they tended to differ in the two samples.

In the chart sample, we somewhat unexpectedly found that Protestant women were much less likely than those who were Catholic to consent to amniocentesis. The Protestant women in our study were, by and large, recent converts to Evangelical sects, which teach that abortion is murder, thereby making fetal diagnosis irrelevant. In contrast, most Catholic women of Mexican origin had more complex, ambivalent, and pragmatic attitudes toward abortion (Preloran and Browner, 1997). They tended to state that while they themselves might be personally opposed to abortion, they could imagine circumstances under which abortion for disability would be acceptable (Press and Browner, 1998; Browner and Preloran, in press). These attitudes are consistent with other research. In a survey of abortion attitudes among 725 Mexico City residents, Nuñez-Fernández and associates found that the vast majority (68.5% of women, 61.4% of men) supported elective abortion in cases of fetal anomalies (Nuñez-Fernández, Shrader-Cox, and Benson, 1994). Why this same pattern was not replicated in the interview sample may have to do with the much smaller size of the interview sample.

A second finding which was significant only in the chart sample was the association between family history of disability and decision to have amniocentesis. Although data from the interview sample were in the same direction, they did not reach statistical significance, again perhaps because of the smaller size of the interview sample. These results, however, are consistent with other research on the subject. Studies of parents of infants with spina bifida in Atlanta, Georgia, by Adams and colleagues (1984) and of mothers of children with Down syndrome in

Memphis and Nashville, Tennessee (Elkins *et al.*, 1986), reveal a complex picture. Although both groups of parents were willing to use prenatal diagnosis in their subsequent pregnancy, particularly in Elkins's study, a great deal of ambivalence was reported as to its value. Only about half said they would abort the pregnancy if Down syndrome were again diagnosed.

It was not surprising that women in the interview sample who had been born in Mexico were more likely to decline amniocentesis. This result supports anecdotal reports of clinicians who work with Latino populations and our own related work on the subject (Press and Browner, 1998). Why the same pattern was not found in the chart sample is not clear.

Our data contrast with those in other studies which find a strong relationship between a woman's screening AFP-positive low or -positive high and her amniocentesis refusal. In those studies, clients who screened AFP-positive high were far more likely to decline amniocentesis than those who screen AFP-positive low (Macri *et al.*, 1996; Benacerraf, 1993). The differences between our results and those in other studies may derive from the differences in the nature of counseling received, for only about a third of the women we interviewed understood the kind of AFP -result they had. In these other studies, counselors may have been more directive in explaining to their clients that in the event of an AFP-positive high, a normal Level 2 ultrasound provides significant reassurance of the absence of a neural tube defect and renders amniocentesis much less informative (Benacerraf, 1993). In our observations, we found counselors far less willing to be openly directive in reassuring patients that a high positive AFP and a normal ultrasound meant that the fetus was likely to be normal.

The much more surprising result was the link between the male partner's presence at the genetic consultation and amniocentesis acceptance in both samples. Contrary to expectation, we found little support for the stereotype that Latinas' low rates of amniocentesis acceptance are because men prohibit their wives from being tested, although this is the reason many women give health care providers for turning down the test (Garcia, 1995; Tatsugawa, 1995).

As our interviews clearly showed, the vast majority of both sexes said it was the woman who made the amniocentesis decision. What this means within the context of any particular relationship or cultural context varies, of course. Rapp (1993b) found in her work on amniocentesis decisions in an ethnically diverse New York City population that out of fear of retribution, some women reluctantly did what they perceived their husbands to want. We saw this only rarely. More often, both characterized the male role as having supported (*apoyado*) the woman in what she said she wanted. The two cases provide descriptive evidence for this pattern.

CONCLUSIONS

This study was designed to investigate the considerations women from Mexican backgrounds who screened AFP-positive took into account when deciding

whether to undergo amniocentesis, as well as the extent to which their male partners influenced the women's decisions. Although we had anticipated that many men would themselves decide about amniocentesis for their wives, this proved not to be the case. Instead, most women decided on their own or in consultation with their male partners. Nevertheless, we found that men played a very important role in the amniocentesis decisions of these Mexican-origin women, particularly those who accepted the procedure. Women who attended the genetic consultation accompanied by their male partners were far more likely to undergo amniocentesis than were unaccompanied women. Our data cannot determine definitively why this is the case. We found that women who accepted were attracted by the promise of reassurance that amniocentesis offers, yet they were fearful of the procedure's known risks. Their husbands, however, were less openly fearful, and they concluded that the reassurance would be worth the risk. In contrast, unaccompanied women found themselves overwhelmed during the genetic consultation by large quantities of new and frightening information and lacked the presence of a supportive partner to help them process it.

What role, if any, ethnicity plays in these observed patterns is an interesting question. Because amniocentesis is not as familiar in Latino culture as it is in some other groups, many women find its prospect frightening (Browner and Preloran, in press). This fact might well make the presence of a supportive partner very important in facilitating acceptance. Yet Latinas are much more likely than women from other backgrounds, particularly European-Americans and Asian-Americans, to attend a prenatal genetic consultation unaccompanied by their male partners. Whether unaccompanied women from other ethnic groups would be similarly likely to turn down amniocentesis is a valuable topic for future investigation.

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